

The efficacy of Appropriate Paper-based Technology for Kenyan children with Cerebral Palsy.

Catherine Barton^{a,b,*}, John Buckley^b, Pauline Samia^c, Fiona Williams^d,

Sue Taylor^b, Rachel Lindoewood^e

^aPhysiotherapy Department, Powys Teaching Health Board, Wales, UK; ^b Centre for Active Living, University Centre Shrewsbury (University of Chester), UK; ^cDepartment of Paediatrics and Child Health, Aga Khan University, Nairobi, Kenya; ^dDepartment of Geography and International Development, University of Chester, UK; ^e Brecon Children's Centre, Powys Teaching Health Board, Brecon, Wales, UK

*Corresponding author: Catherine Barton, Community Paediatric Physiotherapist, Llansantffraid Medical Centre, Llansantffraid, Powys, UK, SY22 6AD

email cath.barton@wales.nhs.uk

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Abstract

Purpose: Appropriate paper-based technology (APT) is used to provide postural support for children with cerebral palsy (CP) in low-resourced settings. This pilot study aimed to evaluate the impact of APT on the children's and families' lives.

Materials and methods: A convenience sample of children with CP and their families participated. Inclusion was based on the Gross Motor Function Classification System levels IV and V. APT seating or standing frames were provided for six months. A mixed methods impact of APT devices on the children and families included the Family Impact Assistive Technology Scale for Adaptive Seating (FIATS-AS); the Child Engagement in Daily Life (CEDL) questionnaire; and a qualitative assessment from diary/log and semi-structured interviews.

Results: Ten children (median 3 years, range 9 months - 7 years). Baseline to follow-up median (IQR) FIATS-AS were: 22.7 (9.3) and 30.3 (10.2), respectively ($p = 0.002$). Similarly mean (SD) CEDL scores for "frequency" changed from 30.5 (13.2) to 42.08 (5.96) ($p=0.021$) and children's enjoyment scores from 2.23 (0.93) to 2.91 (0.79) ($p = 0.019$). CEDL questionnaire for self-care was not discriminatory; seven families scored zero at both baseline and 6 months. Qualitative interviews revealed three key findings; that APT improved functional ability, involvement/interaction in daily-life situations, and a reduced family burden of care.

Conclusion: APT devices used in Kenyan children with non-ambulant CP had a meaningful positive effect on both the children's and their families' lives.

Keywords: Cerebral palsy; resource-limited country; paper technology; adaptive seating; standing frames; assistive devices

Implications for rehabilitation

- Assistive devices are often unobtainable for children with cerebral palsy (CP) in low-income countries.
- APT is a low cost and sustainable solution to make seating and standing devices for disabled children in Kenya.
- The regular use of a postural support device enhanced the children's motor skills, ability to function and participate in everyday activities, reduced the burden of care for the families and promoted the children's social interaction.
- The postural support devices were highly valued and utilised by the children and families in this study.

Introduction

Cerebral palsy (CP) is the most common neurological condition and cause of physical disability in children worldwide, affecting ~1 in 500 live births with lasting impact [1,2]. In Africa, CP is thought to be more prevalent than in most other countries, [3,4]. In 2019, Kenya had 1.75 million live births meaning each year about 3,750 additional children and families will be living with the challenges of CP [5,1]. Approximately 40% of children with CP suffer from a severe non-ambulant form, are unable to sustain a sitting or standing posture [6] and will require therapy support services throughout life [7].

Postural support devices, including seating and standing frames are used as assistive technology therapy for children with CP [8] (Figures 1 and 2).

[Figure 1, Figure 2. Near here]

These assistive technologies aim to overcome children's challenges with motor control due to abnormal muscle tone, co-contraction, loss of selective movement and muscle weakness [7]. For the children and their families, it means more socially interactive, comfortable and functional seated or standing positions, and helps to prevent prolonged periods of lying in one position [8]. Furthermore, improved postural control leads to enhanced function and prevention of deformities and fractures that could lead to further disability [8,11-18]. Frequent sequelae of these motor disorders include hip dysplasia, fractures, muscle contractures and scoliosis which contribute to discomfort for the child and family [20]. These factors lead to significant social isolation from both their families and community. There is therefore a need to find ways to provide affordable seating

and standing frames to promote better growth and development physically and socially [21-23].

In countries with well-resourced health care services like the UK, advanced assistive technologies are provided as part of routine medical and therapy care [7,9,10]. The World Health Organisation (WHO) has reported that assistive technology in low-middle income countries (LMICs) is only available for 5-15% of those requiring them [19]. These data concur with our team's experiences of working with children with CP in Kenya, where assistive devices are rarely provided as part of routine care. Efforts to resolve this challenge have included charitable donations for health technologies but often the donated equipment is unusable for a variety of reasons including; it is not adjustable to the child's ability, size or environment, or when it is broken and there is no one to repair or to adjust it [24-26]. Wooden seating and standing devices have been used in some settings but are expensive to produce locally, are difficult to adapt to the growing child and unaffordable for many families [27-30]. A sustainable low-cost solution to this problem in Africa has been the use of appropriate paper-based technology (APT) [26,31]. These seats and standing frames can be made inexpensively, locally and adapted to the individual needs of the child.

The design and construction process of APT assistive devices has been refined by the charity Cerebral Palsy Africa (www.cerebralpalsyafrika.eu), using recycled cardboard, newspaper and flour-based glue. The production of APT however requires training and the labour can be intensive. Fortunately, there are training courses in constructing APT for volunteers from the children's own community [31]. An APT manual of design, construction and training has now been published based on courses run in Africa [26].

Currently, only anecdotal reports on the physical, psychological and social efficacy of APT exists, which comes from caregivers and those making APT. The opportunity to collect and report more objective evidence on APT efficacy has arisen from a multi-partnership between Aga Khan University, Cerebral Palsy Africa, Powys Teaching Health Board (Wales, UK) and a Kenyan non-government organisation, the St Martin Catholic Social Apostolate (CSA) based in in Nyahururu, Laikipia County. St Martin CSA provides centre-based and outreach services for disabled children and adults, where they have gained considerable experience, in the construction and use of APT. In a three-year period, St Martin CSA produced over one hundred APT devices for the Nyahururu community. The primary aim of this study was therefore to evaluate the efficacy of APT on the quality of and participation in life of children with severe CP in a rural community in Kenya. A secondary aim was to evaluate the acceptability of APT by both the children with CP and their families.

Materials and methods

The research was conducted in partnership with St Martins CSA, Nyahururu, Laikipia County, Kenya. Two staff members from St Martins CSA disability programme agreed to become research assistants for this project and completed an advanced APT course in the UK following a refresher APT course for the wider team at the CSA Centre in March 2015. Ethical approval was obtained from the Scientific and Research Ethics Committee at Aga Khan University, Kenya, including a permit from the NACOSTI [National Commission for Science, Technology and Innovation].

Participant Recruitment

A convenience sample of 12 children with CP were identified through St Martins CSA from families living in the Nyahururu community. At the time of invitation to volunteer, the families were given an illustrated participant information leaflet written in the local languages of either Kiswahili or Kikuyu. A local language interpreter helped answer any further questions about the research.

Eligibility included children meeting the following criteria:

- Aged 1-6 years with a diagnosis of bilateral CP,
- Non-ambulant severe motor dysfunction classified at levels IV and V of the *Gross Motor Function Classification System (GMFCS)*,
- No previous use of a postural support device,
- Able to tolerate and cooperate with detailed assessments,
- For children attending school, they were supported by a caregiver able to transport the APT device to and from school.

There was a bias to recruiting preschool aged children because current models of neuroscience promote the importance of early intervention to foster brain reorganisation and neural plasticity, which is thought to be greatest at this time [33].

Ineligible Families included children with severe uncontrolled epilepsy, due to the possibility of harm resulting from a seizure whilst in the APT.

The Gross Motor Function Classification System (GMFCS),

The GMFCS was used for both sample selection and sample description. It is used internationally as a reliable and validated measure [34,35]. It is a five-level classification that includes a child's current gross motor abilities, limitations in gross motor function and the need for assistive technology and wheeled mobility [36].

Children at GMFCS level IV can sit on a chair but need adaptive seating for trunk control and to maximise hand function. They move in and out of chair sitting with assistance from an adult or a stable surface to pull up on with their arms. Children may at best walk short distances with a walker and supervision but have difficulty turning around and maintaining balance on uneven surfaces. Assisted devices are needed to improve head alignment, seating and standing [37].

Children at GMFCS level V have physical impairments that restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures, and all areas of motor function are limited. For both GMFCS IV and V, children require assisted transport.

Study Design

A mixed-methods design using both quantitative and qualitative data collection techniques was used to strengthen the validity of the research findings through triangulation, with the overall aim of gaining a greater understanding of any physical and social outcomes, including the acceptability of APT. Quantitative results were assessed by a repeated measures design using parent-reported questionnaires. Where possible, inferential statistics were used to verify any changes in the children's function, participation in daily life activities and wellbeing after six months of using the APT device.

The qualitative approach '*in-situ*' sought to explore experiences and perspectives of the primary caregivers of the children. A deductive approach was used in the descriptive phenomenological tradition of seeking to gain the shared experience of the children and

their families [38]. Qualitative data was collected by semi-structured face-to-face interviews with the primary caregivers following six months use of APT, through observations and notes made from scheduled home visits during the intervention, through diary logs of device use and through photographs of the children when supported by the APT.

Study Procedures

Children who met the inclusion criteria had their informed consent given by their parent or carer to participate, including consent for photographs of the children. All photographs included in this article were taken by the research team once consent confirmed.

Each APT device was designed for the child's individual needs following an assessment based on the Oxford Assessment Tool for Complex Disability (Figure 3) [7]. The assessment included determining the child's posture and a comfortable body position (including joint positions) required to be achieved by the APT. The customised APT construction (chair or standing frame) was based on measurements taken by one of the Kenyan research assistants along with a member of the local workshop team. The construction aimed to consider the physical and social needs of the child and his/her stage of current motor development (Figures 4-7). At the time of issuing the APT to the child and family, the primary caregiver was then given both verbal and written instructions on how to use the APT with advice on any pertinent safety issues. The instruction for the caregiver was for the APT to be used at least five times each week, and to use a pictorial diary booklet (Figure 8) to record utilization along with any observed benefits, barriers or problems.

Quantitative outcomes

The research team administering the assessments included physiotherapists, occupational therapists, a paediatrician and the Kenyan research assistants. Changes in posture, motor function and quality of life were measured using the following:

- *Family Impact of Assistive Technology Scale (FIATS – Adaptive Seating) [39, 40].
- Child Engagement of Daily Life questionnaire [41, 42, 43].

*The FIATS-Adaptive Seating was used to evaluate the standing frames because it can detect changes in important aspects of postural device use on family life. The FIATS-AS was “used under license from Holland Bloorview Kids Rehabilitation Hospital, Toronto” for both seating and standing interventions in this study.

[Figure 3. Near here, Figure 4. Near here]

[Figure 5. Near here, Figure 6. Near here]

[Figure 7. Near here, Figure 8. Near here].

Quantitative analysis

Statistical analyses were performed using SPSS version 26. As there were less than 50 participants, normality of distribution was checked via a Shapiro-Wilk’s test [45].

Normally distributed parametric data are presented as mean \pm one standard deviation (SD) and non-parametric data as the median + the inter-quartile range [IQR]. Repeated measures analysis of variance test (ANOVA) and post-hoc paired samples t-tests or a Friedman test were used to determine within-group effects for parametric or non-parametric data, respectively. Statistical significance was set at $p \leq .05$

Qualitative outcomes

Device use

The primary caregivers were asked to record device usage with any positive or negative effects in a simple pictorial diary booklet (Supplementary Appendix 1).

Semi-structured interviews

Research assistants carried out scheduled home visits during the six months' intervention phase. Information from assessment of the children while using the devices during the home visits was documented on the follow-up home visit forms (Supplementary Appendix 2). Photographs of the children using the APT seating or standing devices were taken to illustrate their use (Figure 9).

[Figure 9. Near here].

After six months' device use; face-to-face interviews were conducted with the primary caregivers who had participated for the duration of the study. A semi-structured interview topic guide was used, and the interviews were recorded using an audio recorder. One researcher transcribed and translated the recordings verbatim. Another researcher analysed the data set for semantic themes and consideration of any association with subscale changes detected by the FIATS-AS. These data would help determine which aspects of the intervention were considered useful by caregivers and had an impact on the children's and their families' lives.

Demographics from the Oxford Assessment Tool for Complex Disability provided a profile of the study participants. The qualitative data set from the follow-up home visits and final face-to-face interviews was analysed using a deductive approach and

organised to show patterns of semantic content using Braun and Clarke's [38] 6-phase guide to thematic analysis. Familiarising with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, producing the report. The aim was to report the experiences of the primary caregivers and perceptions attached to the APT devices in regard to the impact of postural support on both children and families. This analysis provided contextual information for quantitative findings, and informed the secondary aim to evaluate the acceptability of APT to the children and perceptions of their participation in the household.

Assessment timelines

Table 1, provides a summary of the timeline when each assessment and outcome measure was performed. Over the six months, there was also an ongoing provision of support by the research assistant. At the end of the six months trial, the primary caregivers completed the FIATS-AS and the Child Engagement questionnaires. The qualitative analyses at this same time point, utilised information from four main sources:

- i. The Oxford Assessment Tool for Complex Disability performed by two different members of the Powys research team; both blinded to the baseline assessment data.
- ii. The diary logs (Supplementary Appendix 1).
- iii. The follow-up home-visit forms (Supplementary Appendix 2), and
- iv. The face-to-face semi-structured interviews with the primary caregivers conducted by the Kenyan research assistant to ascertain perceptions of the APT efficacy.

Results

Of the 12 children recruited to the study, 10 with bilateral CP completed the full 6-month trial using an individualised constructed APT device. Of the two that did not complete, this was due to one family moving away soon after the trial started, and the other family declining to participate for reasons unspecified once they had received the APT. Participant characteristics and APT device use are summarised in Table 2. One child was less than 12 months, and another was seven years old, they were included because this was a pilot study and this intervention was felt to be in their best interests. All children were cared for at home and had spasticity with full ranges of joint movements. One exception was the seven-year old boy who had a dislocated hip and restricted hip and knee movements; therefore, a reclining chair was made for him to maximize posture and comfort.

[Table 2. Near here]

Quantitative analysis

FIATS-AS measure

Table 3. and Figure 10 summarise the changes in FIATS-AS scores at baseline and at 6-months. Observed FIATS-AS subscale values in Table 3 provide an initial illustration of changes that the children and families reported. All but one score, *Contentment* (Δ -1.3%), showed an increased value. The most prominent changes were seen in the

categories of: *Doing activities* ($\Delta 90.5\%$); *Safety* ($\Delta 50.0\%$) and *Parent effort* ($\Delta 45.8\%$).

Given the small sample size and the non-parametric distribution, it was decided not to perform multiple tests of difference on these subscale scores. Thus, the inferential analysis was only applied to the single aggregate FIATS-AS score illustrated in Figure 10, which showed an increase of 33% in the aggregate median score from 22 to 30 (Friedman test, $p = .002$)

[Figure 10. Near here].

[Table 2. Near here].

Child Engagement in Daily Life

Figures 11 and 12 present the descriptive and inferential data of the Child Engagement of Daily Life frequency in participation scores and perception of children's enjoyment at baseline and at 6-months.

For *Frequency in participation in Family Activities* (Figure 11), the APT increased the children's frequency in participation in family activities by 38% after 6 months use (11.58 ($t(9) -2.8$; $p= 0.021$)). There was a corresponding improvement and significant correlation between the activity participation subscale of the FIATS-AS findings and the frequency-in-participation scores ($r_s= 0.657$ ($p=0.039$)).

For *Perception of Child's enjoyment of the Activity* (Figure 12), there was a 30.6% increase in the caregiver perception of the children's enjoyment of the activities after 6 months use of the APT (7.48 ($t(9) -2.85$; $p= 0.019$; 30.6%). This improvement in the

children's enjoyment when doing an activity contrasts with the FIATS-AS child contentment subscale. A Spearman's correlation shows no positive correlation between these measures of contentment ($r_s=0.015$ ($p=0.967$)).

The *Child Engagement Participation in Self-care* was not relevant in seven families who scored zero at both baseline and 6 months. This was due to the severe functional limitations observed based on the GMFCS IV and V levels of the children.

[Figure 11. Near here]

[Figure 12. Near here]

Qualitative analysis

Device use

Eight caregivers recorded details of device use for 8-23 weeks (mean 15wks) in the diary logbooks. One caregiver completed the diary logbook for two weeks only and another completed the logbook with the help of a rehabilitation worker for four weeks retrospectively. These recordings showed that the APT seating was used for 15-60 minutes 2-3 times a day, 5-7 days a week. Standing Frames were used for 15-60 minutes, 1-3 times a day for 4-7 days a week. Two children had usage gaps greater than a week.

There were no additional comments in the diaries from the caregivers regarding positive or negative effects. No adverse events were reported in the logbooks, during the intervention or at the final interviews with caregivers.

Semi-structured Interviews- Caregiver's Perceptions regarding the Impact of the Postural Support Devices

Research assistants visited four families twice during the intervention phase. Three home visits for a further six participants were carried out, but no follow-up forms were completed. After six months device use face-to-face interviews were conducted with all ten primary caregivers who had completed the study. The primary caregiver interviewees were allocated a letter from A to J. This data is summarised in Table 2.

Thematic analysis of the ten transcripts and four follow-up home visit forms produced three themes where APT was of benefit: it had enabled improvement in the children's functional ability, there was greater children's involvement and interaction in life situations, and there was a reduction in the families' burden of care.

Improvement in the Children's functional ability

Nine caregivers reported an improvement in their children's motor ability following use of the device. Excerpts from two of them are presented below;

Caregiver A (child GMFCS V):

“Since this chair was made and she started using it, she has learnt to use her hands, she is able to control her head, and her waist and trunk are now strong in comparison with when she was not using the chair [...] She can sit independently for a few minutes [...] She is able to reach for toys.”

Caregiver C (child GMFCS IV) concurred, stating:

“He has been able to do things differently since he started using his standing frame. He has learnt to use his hands, turn around when seated, change position, shuffle on his bottom and reach out. Before he could only sit and gaze.”

Improved motor skills enabled exploration of their environment and facilitates learning and development. Caregivers observed their children to be more involved in activities of self-care such as feeding and drinking. Caregiver B (GMFCS IV) describes her child as becoming independent at meal times “I am excited nowadays since she is feeding on her own and also holding a cup of tea and milk to drink,” a point also made by Caregiver D “He can now hold a cup and glass and has started feeding himself.”

The data indicates that the seating and standing frames provided postural support to augment motor skills for activities such as self-care and play for children of GMFCS levels IV and V.

Greater Children's involvement and interaction in Life Situations

A related, second emergent theme was the effect of using the postural support devices upon children's interactions and their ability to take part in every-day life. Eight primary caregivers reported that the assistive devices enabled their children to become more involved in family activities at home across all child age groups. The devices facilitated more inclusion, enabling the children to join in with their siblings. “It is possible to involve her in the family activities like watching television and feeding” (Caregiver A), a point further illustrated by Caregiver F, “She prefers using the chair in the evenings when other children are doing their homework” and Caregiver H “He prefers using the chair during lunch time when the other children come home for lunch” Many caregivers reported the utility of the devices as they could be transported and used outside, enabling their children to be more involved with outdoor activities as illustrated by figures 13 and 14. Caregiver G reported “The seat has been quite useful to my son because he's able to stay out and enjoy the sun as he plays with some toys that I place in front of the chair.”

[Figures 13. Near here, 14. Near here]

The data demonstrate that the use of postural support devices can augment interpersonal interactions and a sense of wellbeing, also providing the required postural support to allow greater involvement in activities of daily life such as indoor and outdoor play.

Reduction on the Families' Burden of care

This third theme to emerge from the data was in relation to the postural support devices impacting on the household and the corresponding burden of caring for children with severe disabilities. The majority of the caregivers reported a range of benefits with the time to undertake other duties being a recurring theme. Caregiver B reported:

“I am able to leave them outside playing and go to the market, to the farm and other places where I need to attend to some matter [...] She is also able to give me ample time to do my household chores.”

Less worry about the child's safety was a key factor, as noted by Caregiver A, and supervisory time requirements commented upon by Caregiver D:

“For our part as parents we can now leave her and attend other duties in the farm without fear of her falling over [...] She gives us time to do the household chores and sometimes rest” (Caregiver A).

“I can now attend to other household chores [...] Being able to concentrate on my work without fear of his security and also letting him explore without too much supervision or deciding what is good for him” (Caregiver D).

In contrast, Caregiver J reported being unable to attend to other duties whilst her child was using the device as she needed to support the standing frame manually:

“The child is able to stay in standing position with support. However, I am not able to do other activities when the child is standing because I have to support the aid.”

Whilst Caregiver C reported a greater involvement from other members of the family in caring for their child, “Other family members also help in motivating him to try new things while standing, unlike before.” Overall, the data suggest that the use of postural support devices can reduce the burden of care for families with severely disabled children, however, this theme is mediated by the need to ensure each caregiver understands the safe use of the ATP devices and need to securely fix the standing aid to a sturdy object such as a table or fixed support rather than supporting the aid manually.

Discussion

The results of this study show encouraging benefits to using APT in low-resourced settings. However, there is the need for more research to confidently determine the efficacy of APT. The two core areas of evidence used to demonstrate these positive outcomes were the use of the FIATS-AS and the Child engagement in Daily life assessments. Both parameters were linked to the qualitative caregiver’s perceptions.

FIATS-AS and Caregiver’s insights

Of the nine subscales (Table 3) the four with the highest scores were: the assistive technology device acceptance; the degree to which the children interact socially; the amount

of effort required to assist the children; and the ability of the children to perform activities. These higher scores indicate a greater contribution and importance of these categories to the overall impact of the device on family lives. The technology device acceptance scores indicated that the postural support devices made from APT were highly valued by all the participating families. Coupled with the positive percentage change score, this reinforces the acceptance and utility of the postural support devices by the families in this study. Records from the diary logs showed the seats and standing frames were consistently used throughout the study period. All families chose to keep the APT devices for their children's continuing use after completion of the study.

Improvements were observed in the children's level of family and social interaction and showed that the caregivers believed the children's ability to interact with others was highly important. This finding concurred with other studies [46-48].

Percentage change scores demonstrated that seven of the eight family impact subscale scores showed an increasing positive trend following six months of device use. The greatest effects were reported in the degree to which the children performed activities and their autonomy over their actions. These findings support previous findings that using seating or standing devices enables greater motor function and the ability to perform activities independently [11,12,17,47,49-52].

Further positive trends benefitted the caregivers. Caregivers of the children in the study were mostly mothers, and occasionally members of the extended family. Children with severe CP require more care, attention and direct supervision than children without

disabilities and this caregiving increases with age. Provision of this long-term day-to-day-care often results in caregiver burden and strain [53,54]. This added caregiver burden is associated with poorer psychological and physical health for parents and other family members [39]. In this study positive effects around caregiving were indicated by a decrease in the degree the caregiver worried about their children's safety, which is consistent with the findings of both Ryan et al. [46] and Stier et al. [51]. Other subscales demonstrated a reduction in the amount of effort expended by the caregivers in caring for their children. In most instances and to a lesser extent, the degree to which the carers needed a break from caregiving and the amount of supervision were also influenced positively by the introduction of APT devices. During their interviews, caregivers reported a reduction in the stress and family burden associated with caregiving. These findings are supported by the results from two parental surveys and one case series, where postural support devices were reported to ease caregiving [15,55,56]. Improved functional performance, social interaction and autonomy in children with physical disabilities, all play vital roles in mitigating caregiver burden [46].

Research by Kurne et al. [47] in a parental survey and Ryan et al. [46] in a case series reported that one benefit of customised seating for children with severe CP was enhanced contentment during the day, contradicting the FIATS-AS findings in this study. The lack of evidence for a positive effect on overall child contentment in the FIATS-AS may be due to the long intervention time of six months as well as severe disability in the children, hence limiting some of their social expression. Fuhrer et al. [57] recommend consideration of shorter-term outcomes following the introduction of assistive technology devices. There is evidence for outcomes to be measured after six weeks, allowing families to establish a regular pattern of using a postural support device and enough time to detect the effectiveness, efficiency and satisfaction with the device [46,

58]. This shorter time frame may also mitigate the moderating influence of child development and maturation and other factors such as family, peer and community attitudes.

The significant increase in the FIATS-AS total score (figure 10) showed that the use of APT seating or standing devices had a marked positive effect on the lives of Kenyan families who have children with CP, GMFCS level IV or V. Postural support devices, in addition to having direct therapeutic benefits, play an important role in caregiving by assisting in the daily management of the children at home.

Child engagement and Caregiver's Insights

A significant increase in the children's participation in family and recreational activities was demonstrated by the child engagement in daily life outcome measure (Figure 11). The change in frequency-in-participation mean scores indicated that the equipment increased the children's engagement in family activities. There was a corresponding improvement and significant correlation between the activity participation subscale of the FIATS-AS findings and the frequency-in-participation scores. These results are supported by previous evidence globally [11,12,17,47,49-52, 59].

The self-care element of the Child Engagement in Daily Life questionnaire did not capture any change in participation; seven families scored zero at baseline and again at six months follow-up. This has been previously highlighted by Palisano et al. [43] who reported that evaluating change in severely disabled children with CP (GMFCS IV and V) is a challenge, because some activities such as independent dressing, bathing and

toileting will always be beyond their abilities. Therefore, the *participation in self-care questionnaire* may have insufficient sensitivity to capture meaningful changes in this context of CP childcare and rehabilitation.

The significant increase in the caregiver perception of the children's enjoyment mean scores (Figure 12) established that the APT postural support devices improved the children's level of enjoyment from participating in family activities.

We conclude that APT postural support devices led to a marked positive effect on the children's physical and psychosocial wellbeing, by enabling greater participation in family and community life. The reported themes from caregiver interviews corroborated with this overall positive effect, where APT devices benefited their children and families by enabling greater children's function, increased involvement and interaction in life situations and a perceived reduction in the families' burden of care.

Limitations of Study

Although the study showed important effects on family life due to the intervention, it had limitations. The study design is more prone to bias than other methodologies such as randomized controlled trials or cross over designs. The study attempted to minimise bias by having different assessment teams at baseline and follow up, but a positive bias is still possible. It was a pilot study with a small sample size which was not large enough to make definitive judgements about the contributory effects of the subscales of the FIATS-AS. However, it was sufficiently powered to show positive effects resulting from the introduction of APT postural support devices, except for the participation in self-care questions.

The number of home visits and ongoing therapy was less than hoped for due to capacity issues of the host organisation, which has only one qualified therapist and few employed rehabilitation workers whose updates and remit include spiritual and social support as well as therapeutic input. One researcher completed the thematic analysis.

Conclusion

APT is a low cost locally available and sustainable solution to make seating and standing devices for disabled children in Kenya. The introduction of customised seating or standing devices made from APT had a meaningful positive effect on the lives of families with young children with CP of GMFCS level IV or V. The regular use of postural support devices enhanced the children's motor skills, ability to function and participate in everyday activities, and reduced the burden of care for the families and promoted the children's social interaction. Primary caregiver interviews substantiated these findings. The postural support devices were both valued and highly utilised by the children and families in this study. This pilot study shows it is feasible to conduct research on the impact of APT devices in Kenya and a future study with a larger sample is indicated. In meeting the objectives of the Global Cooperation on Assistive Health Technology (GATE) initiative [60], further research is required to more fully evaluate the effectiveness of postural support devices and specifically the sustainability of APT device production.

Geolocation Information

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Disclosure statement

No potential conflict of interest was reported by the authors.

References

1. Oskoui M, Coutinho F, Dykeman J. An update on the prevalence of cerebral palsy: A systematic review and meta-analysis. *Developmental Medicine & Child Neurology*. 2013; 55(6):509-519.
2. Shevell M, Dagenais L, Oskoui, M. The epidemiology of cerebral palsy: New perspectives from a Canadian registry. *Seminars in Pediatric Neurology*. 2013;20(2):60-64.
3. Donald KA, Samia P, Kakooza-Mwesige A. Pediatric cerebral palsy in Africa: A systematic review. *Seminars in Pediatric Neurology*. 2014; 21(1): 30-35.
4. Gladstone, M. (2010). A review of the incidence and prevalence, types and aetiology of childhood cerebral palsy in resource-poor settings. *Annals of Tropical Paediatrics*. 2010;30(3):181.
5. [cited 2020 27 May]. Available from https://countrymeters.info/en/kenya#population_2019

6. Himmelmann K, Beckung E, Hagberg G. Bilateral spastic cerebral palsy—Prevalence through four decades, motor function and growth. *European Journal of Paediatric Neurology*. 2007;11(4): 215-222.
7. Pope P. Severe and complex neurological disability: management of the physical condition. Oxford, United Kingdom: Elsevier Butterworth-Heinemann; 2007.
8. Cook AM, Polgar JM, Hussey SM. Cook & Hussey's assistive technologies: principles and practice. 3rd ed. St. Louis, Mo: Mosby/Elsevier; 2008.
9. Gericke T. Postural management for children with cerebral palsy: consensus statement. *Developmental Medicine and Child Neurology*. 2006;48(4):244
10. Muggleston MA, Eunson P, Murphy MS. GUIDELINES: Spasticity in children and young people with non-progressive brain disorders: summary of NICE guidance. *BMJ: British Medical Journal*. 2012;345(7868):43-5.
11. Angsupaisal M, Maathuis CGB, Hadders-Algra M. Adaptive seating systems in children with severe cerebral palsy across International Classification of Functioning, Disability and Health for Children and Youth version domains: a systematic review. *Developmental Medicine and Child Neurology*. 2015;57(10):919-30.
12. Audu O, Daly C. Standing activity intervention and motor function in a young child with cerebral palsy: A case report. *Physiotherapy theory and practice*. 2017;33(2):162-72.
13. Capati V, Covert SY, Paleg G. Stander use for an adolescent with cerebral palsy at GMFCS level V with hip and knee contractures. *Assistive technology: the official journal of RESNA*. 2019:1-7.
14. Goodwin J, Colver A, Basu A, Crombie S, Howel D, Parr JR, et al. Understanding frames: A UK survey of parents and professionals regarding the use of standing frames for children with cerebral palsy. *Child: Care, Health and Development*. 2018;44(2):195-202.
15. Ostensjø S, Carlberg EB, Vøllestad NK. The use and impact of assistive devices and other environmental modifications on everyday activities and care in young children with cerebral palsy. *Disability and rehabilitation*. 2005;27(14):849.
16. Paleg GS, Smith BA, Glickman LB. Systematic review and evidence-based clinical recommendations for dosing of pediatric supported standing programs. *Pediatric physical therapy*. 2013;25(3):232.
17. Sahinoglu D, Coskun G, & Bek N. (2017). Effects of different seating equipment on postural control and upper extremity function in children with CP. *Prosthetics and orthotics international*. 2017; 41(1): 85-94.
18. Uddenfeldt Wort U, Nordmark E, Wagner P, Duppe H, Westbom L. Fractures in children with cerebral palsy: a total population study. *Developmental medicine and child neurology*. 2013;55(9):821-6.
19. World Health Organisation. Improving access to assistive technology: report by the secretariat. Geneva, Switzerland; 2016.

20. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol* 2007; 109(suppl 109):8-14.
21. Borg J, Lindström A, Larsson S. Assistive technology in developing countries: A review from the perspective of the convention on the rights of persons with disabilities. *Prosthetics and Orthotics International*. 2011;35(1):20.
22. Matter R, Harniss M, Oderud T. Assistive technology in resource-limited environments: A scoping review. *Disability and Rehabilitation: Assistive Technology*. 2017;12(2):105-114.
23. Visagie S, Eide A H, Mannan H. A description of assistive technology sources, services and outcomes of use in a number of African settings. *Disability and Rehabilitation: Assistive Technology*. 2017;12(7):705-712.
24. Mukherjee G, Samanta A. (2005). Wheelchair charity: A useless benevolence in community-based rehabilitation. *Disability and Rehabilitation* 2005;27(10):591.
25. Pearlman J, Cooper RA, Krizack, M. Lower-limb prostheses and wheelchairs in low-income countries [an overview]. *IEEE Engineering in Medicine and Biology Magazine*. 2008; 27(2):12-22.
26. Westmacott J. Assistive cardboard equipment using appropriate paper-based technology. Galashiels: Meigle Colour Printers Limited; 2015.
27. Borg J, Larsson S, Ostergren P. Assistive technology use and human rights enjoyment: A cross-sectional study in Bangladesh. *BMC International Health and Human Rights*. 2012;12(1):18-18.
28. Kuper H, Monteath-van Dok A, Wing K. The impact of disability on the lives of children; cross-sectional data including 8,900 children with disabilities and 898,834 children without disabilities across 30 countries. *PloS One*.2014; 9(9): 107300.
29. Trani J, Loeb M. (2012). Poverty and disability: A vicious circle? evidence from Afghanistan and Zambia. *Journal of International Development*. 2012; 24: S19-S52.
30. World Health Organisation. World report on disability. Geneva, Switzerland: World Bank;2011.
31. Packer B. Appropriate paper-based technology (APT): a manual. 2nd ed. London: Intermediate Technology Publications Ltd; 1995.
32. Lindoewood R, Bracegirdle C, Samia P. Thinking outside the cardboard box: Insights from a course to train rural Kenyans to make postural support devices from appropriate paper-based technology (APT) for children with cerebral palsy. *Disability and Rehabilitation. Assistive Technology*. 2019; 1: 1-7.
33. Valvano J, La Forme-Fiss AL. Neuromuscular system: The plan of care. In: Effgen SK (ed). *Meeting the Physical Therapy Needs of Children* (2nd ed). Philadelphia: FA Davis; 2013.p 347–388.
34. Palisano RJ, Avery L, Gorter, JW. Stability of the gross motor function classification system, manual ability classification system, and communication function

- classification system. *Developmental Medicine & Child Neurology*. 2018;60(10):1026-1032.
35. Palisano RJ, Rosenbaum P, Bartlett D. Content validity of the expanded and revised gross motor function classification system. *Developmental Medicine & Child Neurology*. 2008;50(10):744-750.
 36. Palisano R, Rosenbaum P, Walter S. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology*. 1997;39(4):214-223.
 37. Palisano R, Rosenbaum P, Bartlett D. The Gross Motor Function Classification System – Expanded and Revised. CanChild Centre for Childhood Disability Research. 2007. Retrieved from http://www.canchild.ca/en/measures/gmfcs-expanded_revised.asp
 38. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology*. 2006;3 (2):77-101.
 39. Ryan SE, Campbell KA, Rigby PJ, Germon B. Development of the new Family Impact of Assistive Technology Scale. *International journal of rehabilitation research*. 2006; 29:195-200.
 40. Ryan SE, Campbell KA, Rigby PJ, Germon B. Reliability of the family impact of assistive technology scale for families of young children with cerebral palsy. *Archives of physical medicine and rehabilitation*. 2007;88(11):1436.
 41. Chiarello LA, Palisano RJ, McCoy SW, Bartlett J. Child engagement in daily life: a measure of participation for young children with cerebral palsy. *Disability and rehabilitation*. 2014;36(21):1804-1816.
 42. Andresen EM. Criteria for assessing the tools of disability outcomes research. *Arch Phys Med Rehabil* 2000;81: S15–20.
 43. Palisano RJ, Chiarello LA, McCoy SW. Use of the child engagement in daily life and ease of caregiving for children to evaluate change in young children with cerebral palsy. *Physical & occupational therapy in paediatrics*. 2015;35(3):280-295.
 44. Chaplin JE, Koopman HM, Schmidt S, DISABKIDS Group. DISABKIDS smiley questionnaire: the TAKE 6 assisted health-related quality of life measure for 4 to 7-year-olds. *Clinical psychology & psychotherapy*. 2008;15(3):173-80.
 45. O'Donoghue P. *Statistics for sport and exercise studies: An introduction*. London: United Kingdom: Routledge Publishing; 2012.
 46. Ryan SE, Campbell KA. Evaluation of a parent-report diary of the home use of assistive devices by young children with cerebral palsy. *Disability & Rehabilitation: Assistive Technology*. 2009;4(3):189-97.
 47. Kurne SA, Gupta AD. Impact of Long-term Use of Adaptive Seating Device among Children with Cerebral Palsy and their Families in Mumbai, India: A feasibility study. *Disability, CBR & Inclusive Development*. 2016;27(3):118-31.
 48. Kurne S, Jayavant S. Optimising Adaptive Seating Solution in Case of Severely Disabled Cerebral Palsy Child. *International Journal of Science and Research*.

- 2017;6(7):318-319.
49. Bolas J, Boyle P. Parental views regarding seating and participation for young children with cerebral palsy, *Journal of Occupational Therapy, Schools, & Early Intervention*. 2017;10(3):254-265.
 50. Rigby PJ, Ryan SE, Campbell KA. Effect of adaptive seating devices on the activity performance of children with cerebral palsy. *Archives of physical medicine and rehabilitation*. 2009;90(8):1389-95.
 51. Stier CD, Chieu IB, Howell L, Ryan SE. Exploring the functional impact of adaptive seating on the lives of individual children and their families: a collective case study. *Disability and rehabilitation Assistive technology*. 2017;12(5):450-6.
 52. Zhang H, Huo H, Hao Z, Tang J, Ji Y, Cao X, et al. Effect of appropriate assistive device on rehabilitation of children with cerebral palsy under ICF framework. *International Journal of Clinical and Experimental Medicine*. 2018;11(11):12259-63.
 53. Dambi JM, Jelsma J, Mlambo T. Caring for a child with cerebral palsy: the experience of Zimbabwean mothers. *African J Disability*. 2015; 4:1–10.
 54. Raina P, Donnell MO, Rosenbaum, P. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*. 2005; 115:6.
 55. Korpela R, Seppänen RL, Koivikko M. Technical aids for daily activities: a regional survey of 204 disabled children. *Developmental Medicine & Child Neurology*. 1992 Nov;34(11):985-98.
 56. Rigby P, Reid D, Schoger S, Ryan S. Effects of a wheelchair-mounted rigid pelvic stabilizer on caregiver assistance for children with cerebral palsy. *Assistive Technology*. 2001 Jun 30;13(1):2-11.
 57. Fuhrer MJ, Jutai JW, Scherer MJ. A framework for the conceptual modelling of assistive technology device outcomes. *Disability and rehabilitation*. 2003 Nov 18;25(22):1243-51.
 58. Ryan SE, Sawatzky B, Campbell KA. Functional outcomes associated with adaptive seating interventions in children and youth with wheeled mobility needs. *Archives of physical medicine and rehabilitation*. 2014;95(5):825-31.
 59. Law M, King G, Petrenchik T. The assessment of preschool children's participation: Internal consistency and construct validity. *Physical & Occupational Therapy in Pediatrics*. 2012;32(3):272-87.
 60. World Health Organisation. Global Cooperation on Assistive Health Technology (GATE). Geneva: Switzerland; 2014. Retrieved from http://www.who.int/phi/implementation/assistive_technology/phi_gate/en/

Table 1. Study Procedures and timeline

Sep. 2015	<ul style="list-style-type: none"> • Identification of six participants
Oct. 2015	<ul style="list-style-type: none"> • Informed consent • Baseline assessments & provision of APT devices
Oct. 2015- Mar. 2016	<ul style="list-style-type: none"> • Device use with caregiver record keeping and scheduled visits
Apr. 2016	<ul style="list-style-type: none"> • Reassessment of participants after 6 months device use with caregiver interviews.
Apr. 2016	<ul style="list-style-type: none"> • Further recruitment of six more participants, informed consent, baseline assessments and provision of APT devices
Apr.–Sep. 2016	<ul style="list-style-type: none"> • Device use with caregiver record keeping and scheduled visits
Sep. 2016	<ul style="list-style-type: none"> • Reassessment of participants after 6 months device use with caregiver interviews.

Table 2. Primary caregiver, participant demographics and type of Appropriate Paper-based Technology (APT) used.

Primary Caregiver	Participant	Age (years)	Gender	GMFCS level	APT type
A	1	2	Female	V	Chair
B	2	5	Female	IV	Standing frame
C	3	3	Male	IV	Standing frame
D	4	6	Male	V	Standing frame
E	5	3	Male	V	Chair
F	6	3	Female	V	Chair
G	7	2	Male	V	Chair
H	8	7	Male	V	Chair
I	9	1	Male	V	Chair
J	10	3	Female	V	Standing frame
	Median (IQR)	3 (2.25)			

GMFCS Gross Motor Function Classification System;

Table 3. Median (IQR) subscale scores of the *Family Impact Assistive Technology Scale-Adaptive seating* (FIATS-AS) after 6 months use of an Appropriate Paper-based Technology postural support device (APT)

	Baseline (IQR)	6 months (IQR)	% change
Autonomy	2.5 (2.2)	3.0 (2.6)	20.0
Caregiver relief	2.3 (0.8)	2.5 (1.2)	8.7
Contentment	3.8 (1.6)	3.8 (1.0)	-1.3
Doing activities	2.1 (3.7)	4.0 (2.1)	90.5
Parent effort	2.9 (2.0)	4.3 (0.8)	45.8
Safety	2.2 (1.3)	3.3 (1.5)	50.0
Social interaction	4.6 (1.4)	5.0 (1.1)	11.0
Supervision	3.2 (1.7)	3.5 (1.2)	7.7
Device acceptance	6.0 (0.8)	6.5 (1.1)	7.5



Figure 1. Adaptive seat used in the UK.

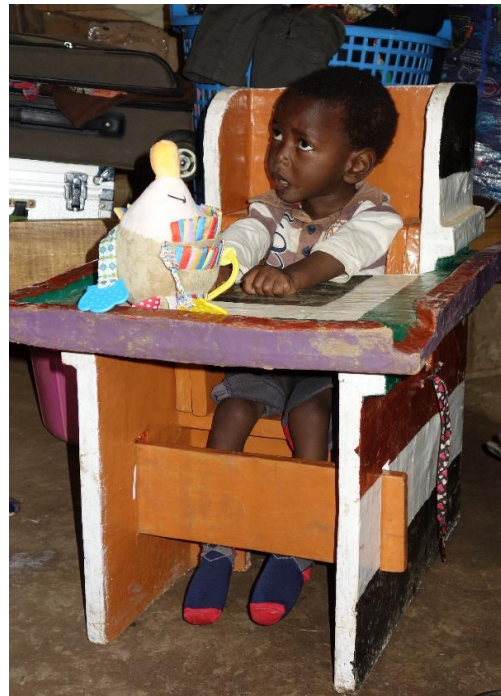


Figure 2. APT device.



Figure 3. Therapist assessing posture.



Figure 4. Child measured for APT chair.



Figure 5. APT device being made and customised to child.



Figure 6. Adjustments for partially constructed chair agreed collaboratively.



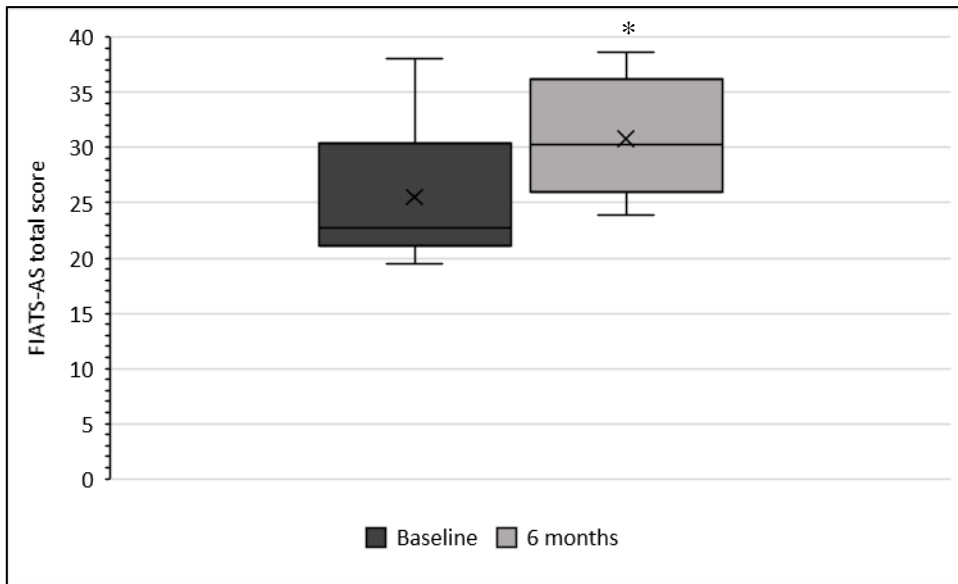
Figure 7. APT Chair ready to take home.



Figure 8. Explanation to the caregiver on positioning child in the APT and completing diary log

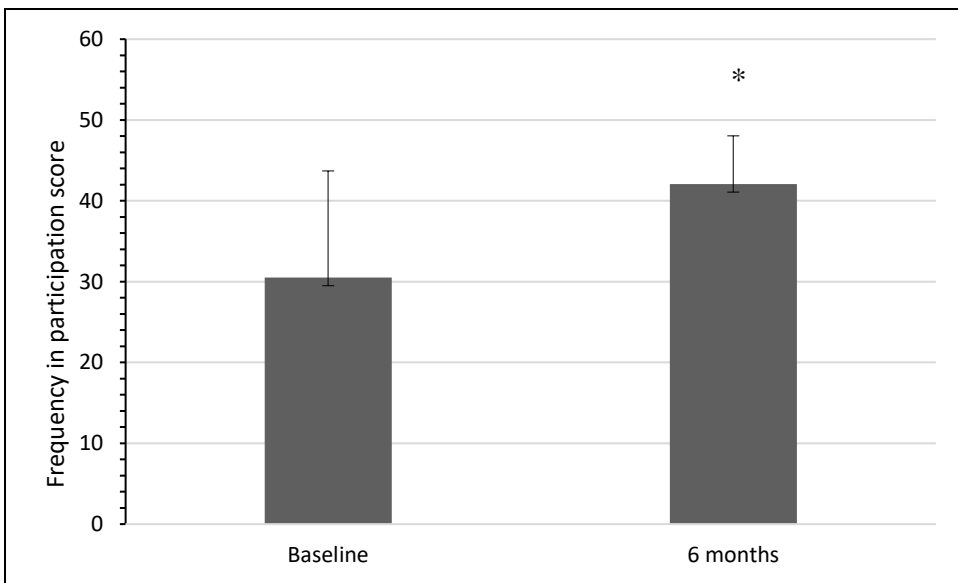


Figure 9. At the follow-up home visit



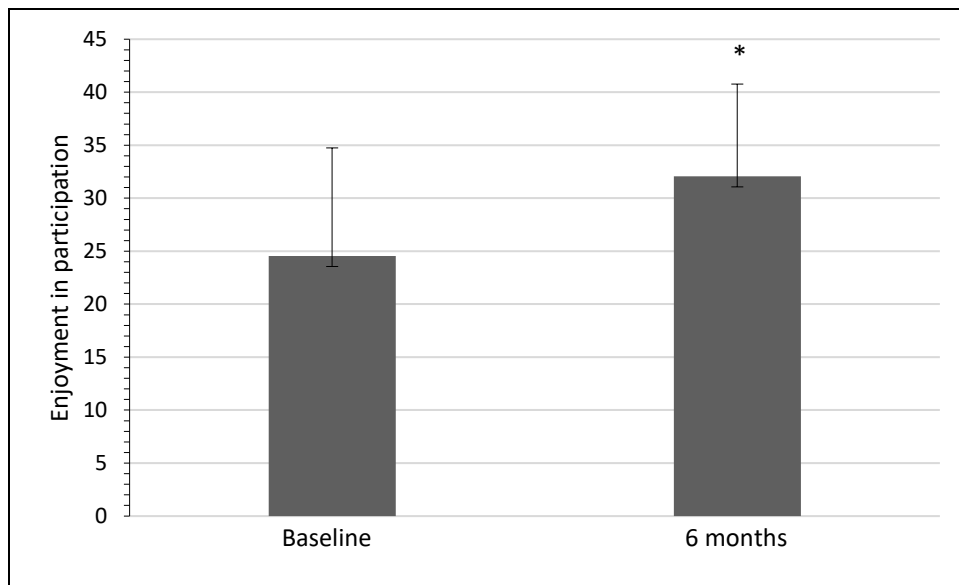
*p=0.002

Figure 10. Median aggregate FIATS-AS score after 6 months use of APT (error bars = IQR). (The score does not include Device Acceptance domain as this was designed as an independent subscale.) *p=0.002



*p=0.021

Figure 11. Mean (SD) Child Engagement Frequency in participation after 6 months use of APT. *p=0.021



*p=0.019

Figure12. Mean (Child Engagement Enjoyment in participation) Mean score at baseline and at 6 months follow-up after APT postural support device use.



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Figure 10. FIATS-AS Median (IQR-error bars) overall score (doesn't include Device Acceptance domain) at baseline and at 6 months follow-up after APT postural support device use.

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Figure 12. Child Engagement Enjoyment in participation Mean (SD-error bars) score at baseline and at 6 months follow-up after APT postural support device use.

Figures 13-14. More involvement in activities outdoors.